Sound Beginnings Early Hearing Detection and Intervention Program 2004 Annual Report

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Background:

Significant hearing loss is one of the most common birth defects in the United States, with an estimated incidence rate of one to three per thousand live births. Every day in the United States, 33 babies are born with a permanent hearing loss. Up to 120 children born each year in Kansas are later diagnosed with hearing loss. Left undetected, hearing loss in infants can negatively impact speech and language acquisition, academic achievement, and social and emotional development. If detected early, negative impacts can be diminished or eliminated through early intervention. Universal newborn hearing screening in the hospital prior to discharge has become standard practice. Without universal newborn hearing screening, the average age of a child diagnosed with hearing loss is between 2 and 3 years of age. With universal screening, hearing loss can be diagnosed in the first few weeks of life.

In 1999, the newborn hearing screening law was established in Kansas. In July of 2004, regulations for the law were passed and the law was amended to require that every baby born in the state of Kansas be given a screening examination for detection of hearing loss, within five days for normal births, or unless a different time period is medically indicated.

Mission:

The overall mission of Sound Beginnings is to minimize or eliminate communication disorders resulting from a hearing loss. This mission can be accomplished in part by following national Early Hearing Detection and Intervention (EHDI) recommendations, often referred to as the "1-3-6 Plan":

All infants will be screened for hearing loss before **1** month of age, preferably prior to hospital discharge.

All infants who do not pass their hearing screening will have a diagnostic evaluation that either confirms or rules out the presence of hearing loss before **3** months of age.

All infants with a confirmed hearing loss will receive early intervention services before **6** months of age.

2004 Program Highlights:

- Kansas received a rating of "Excellent" from the World Council on Hearing Health. An excellent grade implies that almost all babies are screened (90%+), and a statewide system for coordination, training, quality assurance, and follow up has been established. In 2004, Kansas screened 96.8% of babies born before one month of age. Figure 1 illustrates the increase in screening rates from 2002-2004. Kansas began actively tracking individual screening results in July of 2002.

- Kansas was well represented at the 2004 National EHDI conference in Washington, D.C. Sound Beginnings staff, parents and other hearing health professionals attended the conference. There were also presentations provided by a few of the attendees from Kansas.

- Sound Beginnings sponsored a family conference for newly identified infants with hearing loss and their families. Families were invited to attend the conference from Friday through Sunday with all expenses paid by Sound Beginnings federal funds and donations from other various individuals and organizations. Parents attended sessions given by early interventionists, an otolaryngologist, and audiologists.

Supported in part by project 1 H61 MC 00046 01 from the Maternal and Child Health program (Title V, Social Security Act), Health Resources and Services Administration, U.S. Department of Health and Human Services.

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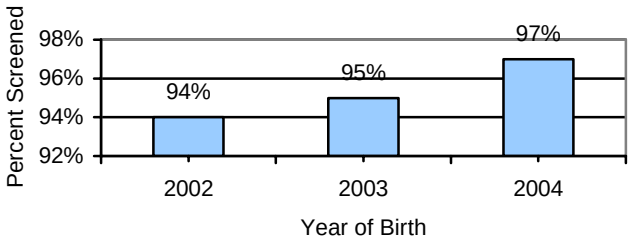
Newborn Hearing Screening Data:

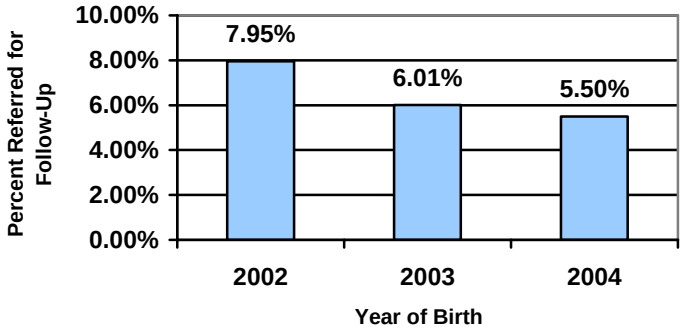
Figure 1 illustrates the percent of infants born in Kansas in 2004 who were screened for hearing loss before 1 month of age. The screening rate in Kansas has increased by approximately two percent from 2003 to 2004. In Kansas, 66% of birthing hospitals screened more than 90% of babies born in their hospital. Last year, less than 4% of infants were not screened prior to discharge in the hospital (3.8%), and less than 1% of parents refused the screening (.24%).

Figure 1: Percent Screened, 2002-2004



Hospitals have shown great success in improving the quality of their screening programs and, therefore, the number of children needing to be referred for additional testing has dropped. As seen in Figure 2, the "refer rate," or the rate of children referred for further testing, declined by one half of a percent from 2003 to 2004. In 2004, there were 67 birthing facilities that provided a newborn hearing screening prior to discharge. Of those 67 hospitals, 13 hospitals used Automated Auditory Brainstem Response (AABR), and 50 hospitals used Otoacoustic Emissions (OAE) screening. The goal regardless of equipment for the state is a refer rate less than 4%.

Figure 2: Percent Referred for Follow-Up, 2002-2004



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One of the main purposes of the newborn hearing screening program is to decrease the average age at which children with congenital hearing loss are identified. Below, Table 1 illustrates the number of infants reported to Sound Beginnings who were born in a given year and have now been identified with a hearing loss, as well as the average and median age at diagnosis. Median age is defined as the age at which half of all cases were diagnosed earlier and half later and is generally a more accurate indicator of the "typical" age. The median and average age at diagnosis has already decreased in Kansas from 2002 to 2004.

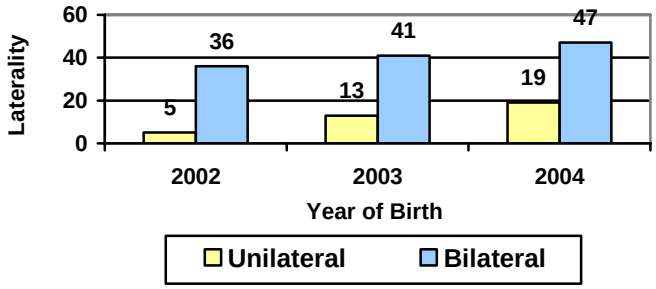
Table 1: Number and Age at Diagnosis With Hearing Loss

Infants born in year	# Diagnosed with Hearing Loss	Median Age at Diagnosis (in months)	Average Age at Diagnosis (in months)
2002	41	2.8	4.3
2003	54	2.75	4.3
2004	66	2.5	3.2

The number of infants currently reported to Sound Beginnings falls short of the approximately 80 expected cases annually based on an incidence rate of two per thousand live births. It is believed that unilateral hearing loss may be a contributor to the shortfall of identified hearing loss cases reported to Sound Beginnings. Sound Beginnings is working with Audiologists to collect every evaluation completed on all newborns diagnosed with a hearing loss using the web-based tracking and follow-up database. This database will provide the means to track more aggressively all infants who have not passed their follow-up hearing screening until a diagnosis of hearing loss is either confirmed or ruled out.

Figure 3 illustrates the comparison of unilateral hearing loss compared to bilateral hearing loss for babies born in 2002, 2003, and 2004. In 2002, 88% of babies were identified with bilateral hearing loss, and 12% were identified with unilateral hearing loss. For 2003, 76% of babies were identified with bilateral hearing loss, and 24% were identified with unilateral hearing loss. In 2004, 71% of babies were identified with bilateral hearing loss, and 29% were identified with unilateral hearing loss. There is an increase of diagnosed cases of unilateral hearing loss reported to Sound Beginnings as seen in Figure 3.

Figure 3: Laterality of Hearing Loss



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2005 Program Goals:

- Collaborate with Part C Early Intervention programs to identify children who are enrolled and have been diagnosed with a hearing loss.
- Contact families and physicians of any children with a confirmed hearing loss to ensure that all families receive the information and services they need.
- Provide funding for the next three years to hospitals with NICU's to purchase Automated Auditory Brainstem Response equipment in order to assist with reducing the number of babies referred for further testing.
- Collaborate with parents and hearing healthcare professionals to start a family support organization specific to hearing loss and an annual family conference.

Definitions:

- **Birthing Facility**: A hospital or facility that has identified itself to the Office of Vital Statistics as having the capability to deliver babies.
- **Referred**: Infants who do not pass their initial hearing screening. These infants should receive a second hearing screening before 1 month of age.

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For more information, please visit our web site at www.soundbeginnings.org.

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